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RESEARCH ARTICLE

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Linking youths' mental, psychosocial, and emotional functioning to ICF-CY: lessons learned

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ABSTRACT

Purpose: Linking ready-made questionnaires to codes within the International Classification of Functioning, Disability and Health, Children and Youth Version with the intention of using the information statistically for studying mental health problems can pose several challenges. Many of the constructs measured are latent, and therefore, difficult to describe in single codes. The aim of this study was to describe and discuss challenges encountered in this coding process.

Materials and methods: A questionnaire from a Swedish research programme was linked to the International Classification of Functioning, Disability and Health, Children and Youth Version and the agreement was assessed.

Results: Including the original aim of the questionnaire into the coding process was found to be very important for managing the coding of the latent constructs of the items. Items from the International Classification of Functioning, Disability and Health, Children and Youth Version chapters with narrow definitions for example mental functions, were more easily translated to meaningful concepts to code, while broadly defined chapters, such as interactions and relationships, were more difficult.

Conclusion: This study stresses the importance of a clear, predefined coding scheme as well as the importance of not relying too heavily on common linking rules, especially in cases when it is not possible to use multiple codes for a single item.

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Mental health; participation; linking rules; adolescents

➤ IMPLICATIONS FOR REHABILITATION

- The International Classification of Functioning, Disability and Health, Children and Youth Version, is a useful tool for merging assessment data from several sources when documenting adolescents' mental functioning in different life domains.
- Measures of mental health are often based on latent constructs, often revealed in the description of the rationale/aim of a measure. The latent construct should be the primary focus in linking information.
- By mapping latent constructs to the International Classification of Functioning, Disability and Health, Children and Youth Version, users of the classification can capture a broad range of areas relevant to everyday functioning in adolescents with mental health problems.
- The subjective experience of participation, i.e., the level of subjective involvement, is not possible to code into the International Classification of Functioning, Disability and Health, Children and Youth Version. However, when linking mental health constructs to the International Classification of Functioning, Disability and Health, Children and Youth Version codes, the two dimensions of participation (the being there, and the level of involvement) need to be separated in the linking process. This can be performed by assigning codes focusing on being there as separate from items focusing on the subjective experience of involvement while being there.

Introduction

In the western world, mental health, especially the mental health of children and youths, is a focus of attention in discussions relating to social functioning and school achievement. According to a systematic review of school factors and mental health, there is a bi-directional relationship between mental health and adolescents' everyday functioning, both within and outside school [1]. The World Health Organization operationalises everyday functioning as participation, as defined and used in the International Classification of Functioning, Disability and Health, ICF, with its Version for Children and Youth, ICF-CY [2,3]. Assessing participation in everyday activities in conjunction with mental health is relevant for planning interventions aimed at supporting everyday functioning in adolescents. Two assumptions are made when using the ICF-CY as a universal language for the documentation of assessment results: (1) we can view adolescent's participation in different life domains as an expression of mental health; (2) the classification system can be used to code mental functioning in

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childhood. In the coding of mental health, the ICF-CY provides a framework for the analysis of the content of measures. Linking rules have been developed and commonly used to facilitate the coding based on the idea that all content of a questionnaire item should be linked even if it means using more than one code for each item [4,5]. However, when items from measures are linked to ICF-CY codes with the intention of using already existing data for statistical analyses, only one code can be assigned to each item. This is a challenge when coding mental health instruments, since many of the constructs measured are latent and, therefore, difficult to describe in single codes.

The ICF-CY classification provides a structure and a coding system to organise information about a person's functioning into four components: Body functions, Body structures, Activities and Participation, and Environmental factors. Each component includes chapters in which categories with associated definitions are listed hierarchically, with up to four levels of detail. The coding system enables the linkage of information to ICF-CY, to facilitate an understanding of the content of information within a model of functioning [6,7]. Information relating to personal factors cannot be assigned codes but can be categorised in the classification. In the Activities and Participation component, the chapters are structured with simple tasks in the beginning of the chapters and complex tasks at the end. Following the same logic, earlier chapters focus on skills, whilst later chapters focus on complex activities, which include the use of multiple skills.

Instruments developed to measure mental illnesses in children and adolescents are usually quite narrow in the areas covered. For example, the Strengths and Difficulties Questionnaire [8] measures five areas: one prosocial area and four areas of difficulty: emotional symptoms, conduct problems, hyperactivity, and peer problems. Other instruments measure psychosomatic complaints, such as headaches, dizziness, and anxiety; as is the case in the Health Behaviour in School-aged Children study [9]. Sometimes, ratings of risk and protective factors provide a more general view of mental health, e.g., instruments measuring children's health-related quality of life, such as DISABKIDS or Kidscreen [10,11]. These health-related quality of life instruments for children and adolescents often differ in content from quality of life instruments applied to an adult population [12], as revealed when coded to ICF-CY. Factors related to everyday functioning such as mobility, self-care, and household work are emphasised in instruments geared toward adults, but not in instruments for children and youths. Transitions from childhood to adulthood are therefore a period when items from both child and adult questionnaires may potentially be necessary to link to ICF-CY codes.

In the ICF-CY model, coding participation is a challenge since the constructs of "activity" and "participation" differ in the model but not in the classification and these challenges become even greater if the two suggested dimensions of participation, "being there" and "being engaged/involved while being there," are considered [13]. This suggestion was confirmed in a study by Maxwell, Augustine, and Granlund where adolescents reported higher levels of involvement in school activities when focusing mentally on what they were doing (i.e., "engaging while being there") [14]. Thus, being highly engaged needs to be measured separately from attending. In linking codes to participation, both whether an item focuses on activity or participation and if the item focuses on attending an activity or level of engagement in an activity while being there need to be considered.

Another challenge relates to coding items that include several meaningful concepts into one main ICF-CY code. The coding rules developed by Cieza et al. [4,5] have been commonly used and multiple meaningful concepts in questionnaire items have been identified through manifest coding [15–17]. Whether the same rules can be used with the intention of identifying only one code per item is an empirical question.

Objective

The aim of the present study was to describe methodological challenges experienced when coding variables intended to measure latent constructs and capture mental health phenomena, e.g., emotions and relations, into the ICF-CY.

The following research questions were asked:

a. What are the challenges in assigning codes to latent meaning to the items when multiple codes per item cannot be used?
b. What chapters in the ICF-CY are covered when items measuring youths' mental health and functioning are linked to ICF-CY codes?

Materials and methods

Instrument

This study used a questionnaire from the first wave of an ongoing prospective longitudinal study of adolescents' functioning and development, within the Swedish research programme LoRDIA (Longitudinal Research on Development in Adolescence). The questionnaire is based on 375 items divided into 25 scales that have been previously used as separate scales and have been validated for scalability in LoRDIA [18]. The research programme aims to study adolescent development (12–13 years of age) and includes the total population of adolescents in four municipalities in the south-west and south-central regions of Sweden.

Linking rules

The linking rules by Cieza et al. [5] were the guiding tool used when assigning ICF-CY codes for each item in the LoRDIA questionnaire. The rules include five specific coding rules and eight general rules for linking information to ICF codes (see Table 1). In addition to these rules, previously suggested solutions regarding child-specific linking issues were taken into consideration [19]. According to these rules and issues, meaningful concepts should be identified using a content analysis process with some level of interpretation [5,19,20]. How items are formulated affects how the linkages are made, especially if an item includes more than one meaningful concept. The length of a meaningful concept and the formulation of a text can also affect the understanding and enable multiple interpretations [21,22]. Therefore, definition of context is crucial and a study-specific coding scheme was set up to overcome the challenges in coding items in relation to mental health and to assign one single code to each item.

Due to underlying interpretations, the linking process cannot be solely manifest and codes on different levels of detail in the ICF-CY system may be required. As stated in the linking rules [5] when assigning items to ICF-CY codes, it is very important to take the aim of the research into consideration when identifying what meaningful concepts to link. This concerns the original rationale for including the whole questionnaire, subscales, and items into the study, as well as the purpose of assigning ICF-CY codes to individual items rather than using the original scales. For the purpose of this study, some modifications of the established linking rules were made to adapt them to our aim. These modifications might not be applicable to studies with other goals.

Table 1. Application and implication of Ciezas et al.'s (2005) linking rules on questionnaire regarding functioning and development in adolescents age 12–13.

Rule in summary	Application	Implication
SPECIFIC RULE		
a. Before linking - Identify all meaningful concepts within each item.	Meaningful concepts are related both to the aim of questionnaire and to the aim of study.	Difficult to implement, smallest unit predefined.
b. Response options are linked if they contain meaningful concepts.	Statistical options, primarily ordinal level.	More relevant for qualitative variables.
c. Interval of time is not linked to the ICF.	Interpreted as "how much time" not as "during a period of."	Instruments might have a "during last week" construct without indicating time.
d. Examples are also linked.	Not performed.	Will create redundant information not used.
e. Before linking, define the aim with which the measure is used in the concrete investigation	Aim of data collection, and aim of specific paper.	Vital for coding and understanding.
GENERAL RULE		
1. Acquire good knowledge of the conceptual and taxonomical fundaments of the ICF.	Both main coders had previous knowledge on the ICF. Coder FL studied the classification further before initiating the coding	Understanding of ICF coding system grew during the process.
2. Each meaningful concept is linked to the most precise ICF category.	The shorter the meaningful concept, the simpler the task. Code that included all aspects of item.	Short items easier, longer items more difficult. Long items more difficult to rate.
3. Do not use "other specified" ICF categories (final code 8) If the content of a meaningful concept is not explicitly named in the corresponding ICF category.	Not necessary to implement in our study.	Not used when having a statistical aim as variables are used on chapter level.
4. Do not use "unspecified" ICF categories (final code 9). Use the lower level category	Not necessary to implement in our study	Not used when having a statistical aim as variables are used at chapter level.
5. If information is not sufficient for making a decision about the most precise ICF category – use nd (not definable).	Used when not possible to code according to ICF. Too imprecise information. If chapter level was identifiable, that level was used.	Items coded only at chapter level cannot be considered when compiling all data.
6. If the meaningful concept is not contained in the ICF but it is clearly a personal factor – use pf (personal factor).	Pf used when personal factors.	Identifies content that needs to be further analysed.
7. If the meaningful concept is not contained in the ICF and it is clearly not a personal factor – use nc (not covered)	When not covered, nc was used.	Identifies content that needs to be handled separately in analyses.
8. If the meaningful concept refers to a diagnosis or a health condition – use hc (health condition).	Diagnosis where coded as hc.	Information not used in functional descriptions.

Linking procedure

Due to the extent of the LoRDIA questionnaire, the linking was performed over a period of 12 weeks, after which discussion and additional linking was performed. One of the main coders (LA) as well as the authors (MA and MG) have previous experience in coding procedures [6,21,23–25]. The other main coder (FL) has earlier teaching experience of the ICF-CY model as well as clinical experience in using the classification when working with children and youth with disabilities. The two main-coders (LA and FL) are members of the LoRDIA research programme and were aware of the intentions with the questionnaire. The different steps of the linking procedure undertaken in this study are described below. An outline on how the linking rules were applied is provided in Table 1.

1. In the first step the two main coders (FL and LA) met to discuss the purpose of the linking as well as the purpose of the instruments that were to be linked. Moreover, the instructions for coding as given in Annex 2 within the ICF-CY (WHO, 2007 p. 249) were studied.
2. In the second step, meaningful concepts within each of the items within the questionnaire were identified independently by the main coders.
3. In the third step, both the meaningful concept(s), and if necessary, the underlying meaning, were first considered independently by the main coders; when questions arose, the two main coders met to discuss.
4. In the fourth step, the main coders independently decided upon which concept was going to represent the item in the linking process.
5. In the fifth step, the decision was made regarding the appropriate ICF-CY category to link to the item.The most precise code possible (e.g., 310 immediate family) was chosen. This was performed by each of the main coders independently.
6. Following the linking procedure, iterative discussions were held to ensure agreement, and the two other authors (MA, MG) were consulted as support coders regarding items difficult to interpret.
7. In the final step, all linked items were re-read several times by the main coder (FL) to see if the linked ICF-CY categories reflected the essence of the meaningful concept.

Calculation of agreement

One way to explore challenges in coding is to look at agreement. Agreement was measured both by percentage of agreement and as Cohen's kappa. When measuring the agreement, only coding from the two main coders was used, that are FL and LA. To investigate similarities and differences in coding a cross-tabulation was used. Agreement was calculated by applying the following rules:

1. Agreement was reached if
   a. the code used was assigned by both main coders, and
   b. the code used was assigned by the main coders on the same level as the index level, i.e., b130 and b1304 for an index on the second ICF-CY code level or b1 and b130 for an index on the chapter level.
2. No agreement existed if

Table 2. Examples and solutions regarding coding challenges in linking procedure.

Challenge	Example	Identification	Solution
Manifest or latent	During a typical week – i.e., Monday to Sunday- how many days in your spare time do you usually follow the news on TV, radio, newspapers or the Internet?	Multiple manifest codes. Options: d115. Listening: d132. Acquiring information; d950. Political life and citizenship.	Decision d950. Political life and citizenship. In a latent structure, the aim of this question is to see how politically and socially interested the person is.
Identification of the emphasis	How do you speak to your parents?	Unclear focus: person, relation or environment? Options: d3. Communication; d7. Relationships; e3. Support from family.	Decision d7. Relationships. In this case, not even latent coding can be completely certain.
Several dimensions within one item	When you come home from school, do you talk about your school day (what you did, your relations to teachers and so forth)?	Too many dimensions.	Decision d350. Conversation. Using the simplest latent one.
Coding activities and participation in risk behaviours	During the last 12 months, have you ever used narcotics?	Interval of time No variable for risk behaviours.	Decision d570. Managing one's health Interval of time is not included in ICF (see rule). However, it differentiates from ever using.
Perspective in relational questions – child or another person	Do your parents know what you spend your money on? My sibling is a close friend.	Unclear interrelationship: whether the family members give support, or the student's perception based on own actions. Options: d760. Family relationships; e310. Immediate family.	Decision e310. Support from immediate family Simplest coding.
Frequency or engagement? Activity or participation?	Item 1: How often do you arrive at school on time *vs.* item 2: how important is it to arrive at school on time?		Decision: 'How often' = frequency; 'How important' = engagement. Using the domain code and dividing variables in frequency and engagement.

a. both main coders coded equally, but the final code differed due to post hoc discussion with the two support coders, or
b. coders did not code equally, even if the support coders agreed with one of the main coders.

Results

Challenges encountered are captured in two ways: In Table 2, an overview of challenges encountered in the linking procedure is presented while Table 3 illustrates pattern in coding, thus indicating where difficulties were encountered. Based on chapter level in the ICF-CY, agreement was reached for 287 out of 374 codes, generating an agreement percentage of 76.7. Cohen's kappa value was 73.4% (0.734). Specific topic areas for challenges concerned chapter d7, "interpersonal interactions and relationships;" e3, "environmental support and relationships;" and e4, "attitudes within the environment." Other challenges concerned d2, "general tasks and demands" and b1, "mental functions." In addition, d2 "general tasks and demands" had low overall agreement (Table 3).

Items in the LoRDIA questionnaire that were relatively easy to assign a code showed a common attribute; the questions and the original purpose of the questions asked, referred to the same ICF-CY chapter, i.e., topic area. This indicates that, when there were problems with reliability for separate items within these scales constructed in the linking procedure, it was due to difficulties in coding the items into single ICF-CY chapters rather than being inherent within the original scales. In coding to ICF-CY, we in particular had difficulties with items measuring the relation between people and interactions, i.e., should a d-code referring to the person or an e-code referring to the environment be used.

Discussion

Data from the first wave of the LoRDIA study on development in adolescence were used to describe challenges in the process of linking questionnaire items based on latent constructs into ICF-CY codes. The findings explored which ICF-CY chapters were covered by items in a questionnaire designed to measure mental health and everyday functioning in adolescents.

Challenges in assigning codes to latent meanings

Several challenges experienced in assigning codes to latent meaning in the mental health questionnaire items were related to the fact that multiple codes per item could not be used due to the purpose of statistical analyses. These challenges included (a) developing rules for linking item content in a manner that retained the conceptual meaning of the latent constructs as intended by the original questionnaire's aim; (b) selecting the latent construct to be represented by one ICF-CY code for items related to ICF-CY chapters representing broad aspects of functioning; and (c) selecting the most representative code for the latent construct when linking items containing several manifest meaningful concepts.

ICF-CY chapters covered

The linking procedure performed in this study, using an existing questionnaire within the Research programme LoRDIA, shows that not all chapters within the ICF-CY are covered. The components body structures and body functions – with the exception of "mental functions" (b1) – seem less relevant when estimating mental health for a general population. The same seems to apply for two of the chapters belonging to the component Activities and Participation: "learning and applying knowledge (d1) and "mobility" (d4) (see Table 3). Other chapters are well represented, especially "interpersonal interactions and relationships" (d7). This is likely to be related to the particular latent construct the original scales aimed to capture. Regarding mental health instruments, a relatively narrow focus on emotions and relations was revealed, with little attention given to everyday functioning regarding learning, personal care, mobility and home life. A conceptual discussion on why some chapters are represented while others are not,

Table 3. Chapter-level coding pattern for coder 1 and coder 2, indicating both prevalence of agreement and disagreement.

	Coder 1 (FL)																
Coder 2 (LA)	b	d1	d2	d3	d4	d5	d6	d7	d8	d9	e1	e3	e4	e5	nc	sum	%
b	51		20			1		5								77	66
d1										2						2	0
d2			6													6	100
d3				9					2							11	82
d4	1				2											3	66
d5	2					18										20	90
d6							8		1							9	89
d7				1				42		2		3	4			52	81
d8			1						7		1	5				14	50
d9										8						8	100
e1											7					7	100
e3								3				63				66	95
e4			1					10		1		8	35			55	64
e5									1							1	0
nc			1										11		31	43	72
Sum	54	0	29	10	2	19	8	60	11	13	8	79	50	0	31	374	
%	94	0	21	90	100	95	100	70	64	61,5	87,5	80	70	0	100	76,7	

Footnote: nc stands for not codable, all reasons for not coded are included. Both coders coded 374 items. Columns indicate how coder 1 coded and rows how coder 2 coded. The diagonal illustrates agreement per chapter. The % column show agreement percentage.

related to the aim of the study, is thus needed before linking is implemented.

Lessons learned

Regarding mental health, our focus on adolescence as a transition between childhood and adulthood made it necessary to search the literature for age-related differences in content on mental health instruments. It revealed that child and youth instrument measure the focus on emotions and relations while adult instruments also seem to include managing everyday-life. Independence and managing adult role-expectations require skills in managing everyday-life. Seeing adolescence as a transition made it necessary to include items encompassing emotions, relations and managing everyday-life. Thus, the LoRDIA questionnaire's latent constructs as well as individual items were discussed in depth to ensure that all these hypothesised aspects of mental health were covered.

Our focus was on applying the linking rules provided by Cieza et al. [5] when coding the aim of the original scale and question, i.e., the specific latent construct they were intended to measure. This required a critical discussion of linking rules as recommended by the World Health Organization. The specific "Rule a" (to identify all meaningful concepts within each item before linkage) needs to be discussed and if necessary, put aside, whilst "Rule e" (to define the aim with which the measure is used in the concrete investigation) should include the purpose of the study, the original aim of the questionnaire, and the aim of each section/subscale in the questionnaire. Both the perspective of the question at hand, e.g. difficulties, needs, satisfaction, or dependency, and the context for asking need to be clarified. On the other hand, "Rule d" (to link examples) creates redundant information (see Tables 1 and 2).

"Rule e" (before linking, define the aim with which the measure is used in the concrete investigation) is vital and can both create and explain difficulties in agreements. This became apparent when using external raters not accustomed to these aspects, such as the aim of the instrument, data collection, and re-coding. Some of the issues discussed above are partly addressed in the recently published refinements of the linking rules [26], which we understand is the result of a second update of the rules and is much appreciated in the light of our results.

A focus on emotions and relations is common in instruments aimed at measuring mental health in adolescents. This focus on the interaction between person and environment means that the original scales to be linked contain items related to more than one ICF-CY domain, for instance when either mental function (b1) or functions related to general tasks and demand (d2) can be linked or when either interpersonal relationships (d7) or support (e3) can be linked. Such overlaps generated coding difficulties, potentially because the content of these chapters concerns relationships within context, i.e., the phenomena of interest defined by the person, the task, and the environment. The overlap between content in different ICF-CY domains not only makes it important to identify the smallest meaning unit in the item, but also to have in mind the type of content aimed at in the linking.

One way of resolving the issues regarding how to identify the most representative code for a latent construct is to explicitly identify what the item was originally intended to measure and then search the ICF-CY code that incorporates as many aspects/meaning units as possible in the item, i.e., the most complex code possible. In our analyses, we can see that codes from chapters containing more complex activities, e.g., chapters d7–d9, were preferred and, therefore, more often coded. One challenge of using only one code is the possible loss of information as codes can, on a more complex level, incorporate information on different areas. Therefore, if the ICF-CY constructs are statistically tested, more complex and generally termed chapters should pose challenges creating indexes with high consistency. This is also likely to be the case for environmental chapters that are very generally termed; therefore, items representing environmental areas can differ and yet be assigned the same code. Potentially, chapters with a lower level of complexity will be more easily assigned an index with high consistency.

Many items representing constructs described as personal factors in the ICF-CY were, in our linkage procedure, assigned codes related to body functions and, more specifically, to temperament and energy functions (b126) or emotional functions (b152). Some examples of this are confidence, loneliness, independence, self-determination, sadness, anxiety, happiness, anger, and future concerns, that can all be more or less contextually dependent [20,27]. There is an ongoing discussion as to whether personal factors in the ICF-CY model should be used or applied before the component is given a clear definition, to avoid overlap with other ICF-CY components [24]. We therefore suggest not using personal factors for coding until consensus has been reached on what the factor

contains and how personal factors can be differentiated from mental functions.

When deciding whether an item with a latent content is possible to link to a single code, the previously used linking rules [5] need to be adapted. This study can be seen as one step in that direction. Many aspects need to be taken into consideration, such as the characteristics of the ICF-CY system, the linking rules, and the aim and content of the original questionnaire. In addition, the linking must be based on the aim of implementing the linking of items.

Limitations of the study

One crucial weakness in the present study was the difficulty of ensuring that all coders interpreted items similarly. This is especially relevant when only one code can be used to represent an item. We used several coders, who sometimes interpreted item content differently. The importance of discussing aims of the original questionnaires, aims of the study, and, if relevant, aims of the ICF-CY before linking, must be stressed.

Some items in the questionnaire had two responses for one question, which means that, when we linked these items, we only assigned a code to the item, not to the responses. This is relevant when answering, for example, questions about mother and father separately.

Suggestions for future research

Further studies could investigate the use of the code "other specified," which was not used in this study due to the linking rules proposed by Cieza et al. (2005). The recently published refinements of the linking rules encourage the linker to use the code for "other specified" if a linkage of aspects of functioning is not included within any of the other specific categories – not only on second level codes, but for a whole block of codes. This would broaden the content of the code and, most likely, make it easier to decide on one single code for the whole item, in addition to cases where more than one meaningful concept could be found. This is illustrated by Ibragimova Klang and colleagues [21], who found that the size of an item is essential for a decision on the content in a meaningful concept. Moreover, challenges related to reliability when assigning codes to latent constructs with the aim of generating information to use in inferential statistics need to be explored.

Conclusion

The understanding that manifests coding is the gold standard and is a challenge when coding latent constructs – such as mental health with the intention of using existing data for statistical analyses. Latent constructs related to mental health have repeatedly been operationalised into several items that can contain more than one meaningful concept per item. For example, items related to interpersonal interactions and relationships (d7) can also be linked to support and relationships (e3). These kinds of overlap between the content in different ICF-CY components and chapters are dependent on whether body, activity, and participation or environment is in focus. For this reason, it is important not only to identify the meaningful concept to link in the item but also to have in mind the type and content of information aimed at in the linking procedure. This study indicates that some of the linking rules suggested by Cieza et al. [5] are difficult to apply in a coding process where the statistical usage of the indexes is the reason for coding. The underlying latent content should be the basis of the coding procedure. The results from this study underscore the relevance of the refinement of the linking rules presented by Cieza et al. [26].

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